DINET
Dysautonomia Information Network

April 2018

Dear friends,

At the end of the summer of 2017, DINET conducted an informal survey to explore the age of onset of symptoms, diagnosis and the overall diagnostic process for women with dysautonomia disorders.

Members of the DINET site, visitors and followers of the DINET Facebook page were all invited to participate. This survey is in no way scientific research, and the answers given were not validated in any way. It is a sampling of information and subjective experience from a segment of our audience.

The purpose of this informal survey was to identify some factors and experiences that may impact the level of care during the diagnostic process. It also provided DINET with a sampling of ages from our respondents and length of time taken to receive a diagnosis of dysautonomia.

This survey was very important to DINET. It identified areas of study and pathways that we can better provide support and education. DINET greatly appreciates everyone who took the time to answer the questions and share so much of their personal history with us. Special thanks to Trudi Davidoff who wrote the survey and compiled the results.

Questions or comments about this survey should be sent to webmaster@dinet.org

Best regards,

Ellen Driscoll

Ellen Driscoll, President
Board of Directors
Dysautonomia Information Network
ellen.driscoll@dinet.org

Women's Age Onset Dysautonomia Survey.

Our Words Matter, Our World Matters.

Survey Analysis report By Trudi Davidoff, General Member of DINET Board of Directors.

Thank you to DINET, its members and volunteers. It has been an honor and rare privilege to learn and understand the effects of dysautonomias by reading our own words. Through written descriptions, our members have provided a rich documentation of insight creating discernable pathways to better patient care and diagnosis.

Recommendations for pathways are *in italics* after each question analysis. (Questions 2 and 3 are 'age only' answers and have been grouped together for analysis and recommendations.)

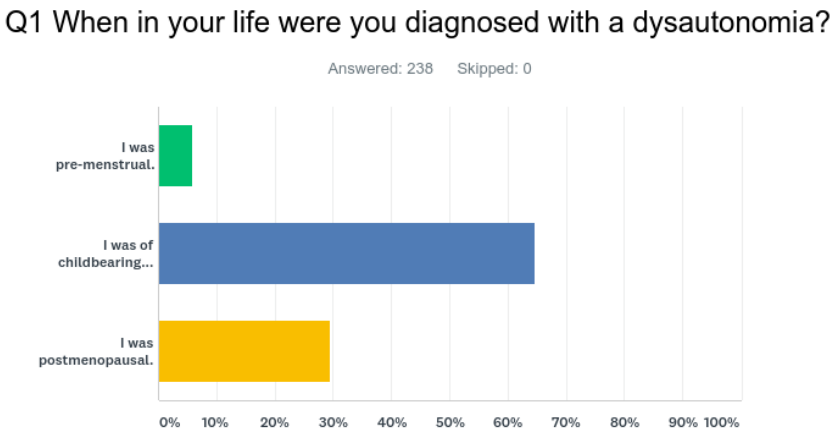
The survey, created with SurveyMonkey.Com, ran from July 8, 2017 through September 3, 2017. 238 participants replied to the survey.

Question 3 had 237 responses with one skipped, Question 6 had 237 responses with one skipped. Question 7 had 229 responses with nine skipped, Question 8 had 229 responses with nine skipped.

The survey provided some illustrations for our report. Questions 1, 4, 5, and 6 have Bar Chart Graphs demonstrating a clear representation of results. Questions 2, 4, 5, 6, 7, and 8 have Word Clouds. All text replies created Word Clouds. For increased visual clarity I have also listed the graphic words and numbers with tables.

To filter the responses for the survey analysis, the top words from each cloud list have been selected to show a range of replies and searched through the responses in order of list strength. Some replies have two or more sample words; effort was made to remove duplicates responses in the samples. Some replies how an overlap of sentiment but have been selected for their different perspective. Respondent replies have been left in their own text with no changes to grammar or syntax; the only changes noted are to remove identifying names or expletives. The only identifier to any particular reply is its time stamp. In this analysis the cloud words of some text responses could be divided into smaller subgroups, this is especially seen in Questions 7 and 8 with their 'Text Only' responses. These subgroups are identified with *italic headings*.

Question 1: When in your life were you diagnosed with a dysautonomia?



Questions	Response %	Number
I was pre-menstrual.	5.88	14
I was of child-bearing age.	64.71	154
I was post-menopausal.	29.41	70
Total		238

Nearly 30% of the respondents were diagnosed post-menopausal and 6% as girls, together over a third. (5.88 + 29.41 = 35.29%).

Questions 2 and 3 were written in mind to determine how long we have lived with our dysautonomias as well as determine if the longer we have lived with them or the older we are that the pre-diagnostic care included medication with mood-enhancing drugs. In the next phase of analysis these ages will be compared to see if there is a curve—that the older one is the more likely they are to have a delayed diagnosis.

Question 2 had 238 responses, Question 3 had 237 responses with one skipped.

Question 2: How old were you when you were diagnosed?

Words from this unexpected small cloud were not analyzed for this survey.

Q2 How old were you when you were diagnosed?

Answered: 238 Skipped: 0

Respondent diagnosis ages ranged between 11 and 79.

Age	#		Age	#		Age	#
11	2		36	8		61	1
12	4		37	6		62	3
13	3		38	6		63	2
14	3		39	2		64	2
15	5		40	5		65	1
16	3		41	4		66	0
17	7		42	5		67	0
18	2		43	11		68	2
19	3		44	5		69	1
20	6		45	6		70	0
21	1		46	6		71	0
22	7		47	5		72	0
23	1		48	9		73	1
24	6		49	3		74	1
25	3		50	4		75	0
26	6		51	2		76	0
27	2		52	8		77	0
28	2		53	4		78	0
29	2		54	5		79	1
30	3		55	4		80	0
31	3		56	2		81	0
32	3		57	3		82	0
33	5		58	3		83	0
34	7		59	3		84	0

35	9		60	3		85	0

Question 3: How old are you now?

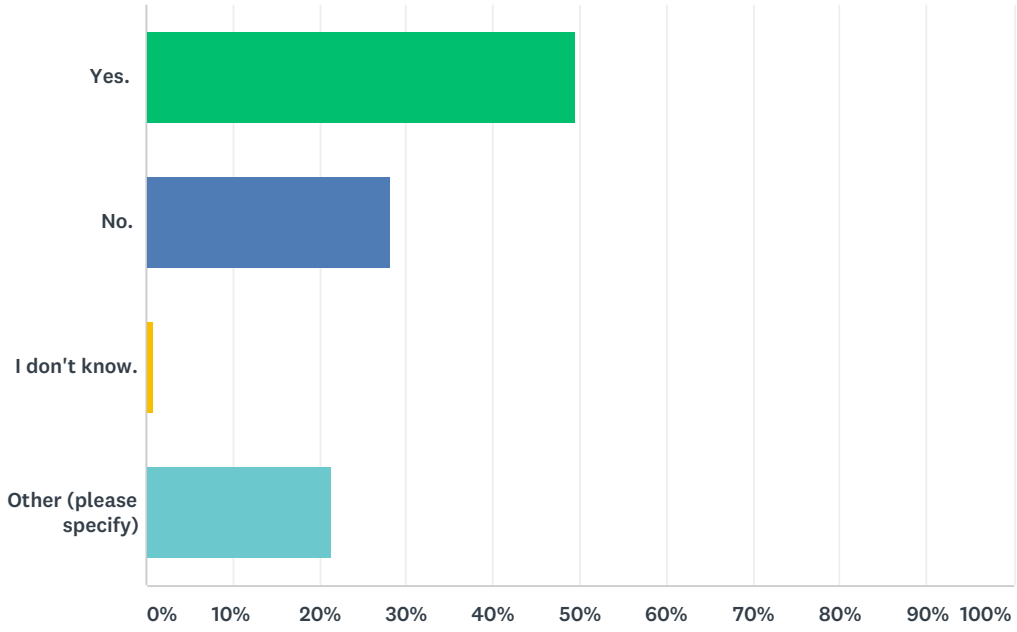
Word Cloud: No important words or phrases were found. So, there's no cloud.

Age	#		Age	#		Age	#
12	1		36	6		60	6
13	0		37	3		61	3
14	1		38	5		62	3
15	1		39	5		63	4
16	2		40	2		64	1
17	3		41	4		65	1
18	3		42	1		66	3
19	2		43	4		67	1
20	4		44	6		68	2
21	1		45	7		69	0
22	6		46	5		70	4
23	2		47	9		71	0
24	6		48	5		72	1
25	2		49	7		73	1
26	5		50	6		74	1
27	3		51	5		75	1
28	5		52	5		76	1
29	2		53	5		77	0
30	4		54	6		78	0
31	4		55	7		79	0
32	5		56	1		80	1
33	5		57	9		81	0
34	3		58	8		82	0
35	4		59	6		83	0

Between ages 45 and 60 we see a larger number of responses. Within a decade, the medical community which specializes in geriatrics will see an increase in patients diagnosed with dysautonomia. Being able to recognize and differentiate symptoms typical of age and dysautonomias may present diagnostic complications because symptoms like insomnia, brain fog, imbalance, and short-term memory loss can be attributed to dementia, unstable BP and HR readings, GI problems like GERD, motility and incontinence, painful muscles and joints, and vision changes are all normal for aging and may mask dysautonomia symptoms.

Q4 When you described your symptoms to a health care professional were you prescribed a sedative, antidepressant drug or told to seek psychiatric help?

Answered: 238 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes.	49.58%	118
No.	28.15%	67
I don't know.	0.84%	2
Other (please specify)	21.43%	51
TOTAL		238

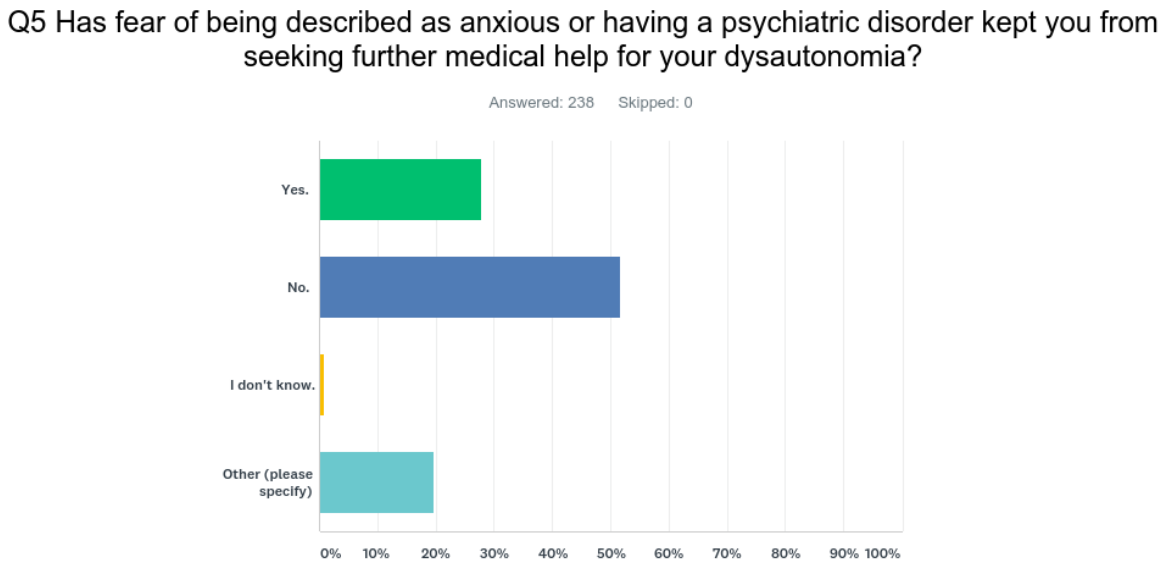
#	OTHER (PLEASE SPECIFY)	DATE
1	Psychological Not prescribed anything. Was told, "Sometimes the body plays tricks on the mind."	9/3/2017 11:01 AM
2	Prescribed Non Narcotic Midrine	9/2/2017 9:07 PM
3	Prescribed Non Narcotic My son was diagnosed first. Then, my other children were coming down with symptoms. My son was put on florisef we all changed our diets due to trial and error. Told our cardilologist that we were glutennfree,dairy free,sugar free.	8/31/2017 3:40 PM
4	Psychological Most of my doctors were very good, compassionate, and believed me even when they couldn't figure out what was wrong. As a teenager I did have one doctor who oversaw one of my tests, and he told my mom afterward that there was nothing wrong with me and that I was making it all up. Thankfully, my parents believed me. In recent years, even after 20 years of dysautonomia, numerous documented tests, many top-level specialists who have seen/diagnosed/treated me, I have had trouble again with a physician who didn't believe me. It was quite a shock. A doctor who supposedly treats dysautonomia wrote in my medical record that my problem is psychological. He ignored my previous medical records and the specialists who have diagnosed me and who treated me for many years. There are no other doctors in my area who treat dysautonomia, so I am now without a dysautonomia specialist within a day's drive.	8/31/2017 2:45 PM

5	Does not apply I	8/31/2017 12:19 PM
6	Psychological Yes, i was told my symptoms at age 13 were "panic attacks" and no one researched any further.	8/31/2017 11:56 AM
7	Other Health Condition Prescribed Non Narcotic Told to be very careful when going from a laying down to sitting to standing position --then told at 14 it might be due to hypothyroidism & put on thyroid	8/31/2017 11:29 AM
8	Does not apply I was lucky enough to see a ME / CVS doctor who recognized the POTS before I had the idea that it could be POTS.	8/31/2017 10:19 AM
9	Psychological My doctors believed me. They suggested psychiatric help for the stress and learning how to work through the life changes.	8/31/2017 10:00 AM
10	OTC drug Other Health Condition they said i had gas or made it up. gave gaviscon	8/31/2017 9:06 AM
11	Other Health Condition Was sent straight to cardiologist due to tachycardia episode	8/29/2017 8:45 PM
12	Prescribed narcotic I have been to many neurologists as I have a cyst on the brain. They said it was asymptomatic so we looked for another cause. I was found deficient in Vitamin B12, Folate and Vitamin D. That contributed to small fibre neuropathy and dysautonomia. There are still issues which my specialist believes are due to a rare condition. At the start most doctors dismissed my Neuro symptoms despite the clinical issues which might explain them. I had to research myself to find a consultant who would look deeper...and she did. This led to diagnosis or at least confirmation of SFN, POTs and Autonomic Dysfunction. I thank God I found her. I was only offered pain relief. Morphine.	8/29/2017 7:30 AM
13	Psychological Told its in my head, I'm crazy. I take too many supplements indicating it a mental illness. But never actually told to get psychiatric help. In fact, was refused a psych consult.	8/25/2017 9:15 AM
14	Psychological i had a recent flare up where i was told to seed psychiatric help	8/19/2017 9:23 PM
15	Other Health Condition The doctors didn't know what it was	8/13/2017 4:37 PM
16	Psychological I've had POTS symptoms since I was about 10. It was never a focus until I was 23 and presented with resting tachycardia (120bpm). In the interim years, I was treated for many psychiatric issues (namely anxiety and depression) without any evaluation of my physical state beforehand.	8/12/2017 12:50 PM
17	No physical source Psychological They thought anyone talking about so many symptoms was making it up. I was rd that no one could have all these symptoms. That it wasn't possible.	8/11/2017 11:19 PM
18	No physical source Psychological I was told my symptoms were most likely emotional (anxiety, depression) as they could not find definitive physical abnormalities at the time.	8/9/2017 2:38 PM
19	Prescribed narcotic Antidepressant	8/7/2017 1:00 AM
20	Does not apply Other Health Condition I had a few episodes in my early 20's and was told I was just dehydrated. But at 34 I was having frequent episodes and were taken more seriously.	7/30/2017 9:32 PM
21	Prescribed narcotic Psychological 17 years ago I had symptoms and was told I had panic anxiety and was put on benzodiazepines and SSRI meds. I was diagnosed recently at age 52. When I went to ER and all tests normal. Dr asked if I could possibly have anxiety. A week later, I saw a cardiologist who told me in first visit he was thinking of a dysautonomia diagnosis.	7/29/2017 3:26 PM
22	Psychological I was told by a couple of doctors to seek psychiatric help, while others thought I could be having some mental issues that could eventually be worked out as time went by.	7/28/2017 3:39 PM
23	Psychological i was told that there was nothing wrong with me and that did i think i was like one of these athletes who might fall down and die	7/27/2017 2:59 PM
24	Psychological I was asked psychological-type questions by a GI Dr. such as...have I ever thought of hurting myself etc. He was convinced I was trying to hide an eating disorder.	7/22/2017 10:03 PM
25	Other Health Condition Not initially. My bp was so low and they didn't know what to do. A nurse told me to see a cardiologist who specialized in pots. I don't have pots	7/18/2017 8:32 PM
26	Psychological Years before my actual diagnosis I was told to see a psychiatrist. I refused. About 10 years after that I was diagnosed after a major episode. First I was sent to a nuerologist and he referred me to an electrophysiologist. Tilt table test and thats the end!	7/18/2017 8:17 PM

27	Prescribed Non Narcotic Prescription salt tablets, exercise plan specifically for pots. I was just diagnosed last week (7/11/17)	7/18/2017 3:18 PM
28	Prescribed narcotic Psychological I was told it was all in my head and given prescription of Xanax	7/17/2017 8:07 PM
29	Psychological No, but I always got the feeling that they thought there was a psychiatric componet to my symptoms.	7/15/2017 5:51 PM
30	Psychological She looked at me like I was making it up and exaggerating.	7/15/2017 5:40 PM
31	Psychological I was in the ICU and I had a health care professional tell me 'You can be unwell at home'. My neurologist properly diagnosed me and referred me to Mayo Clinic	7/14/2017 9:04 PM
32	Other Health Condition Psychological I was diagnosed with anxiety, depression, IBS, chronic fatigue at age 24 till my proper diagnosis at 48. I also had Coeliac disease diagnosed at 44. yrs. I had obviously had that all my life undiagnosed.	7/14/2017 8:37 AM
33	Prescribed narcotic Psychological In the beginning my internist kept pushing anti-anxiety meds. Even now that she knows what I have and what another out of state doctor prescribed, she still wonders why I'm not on an SSRI (she has a couple of other POTS patients and that's what they take).	7/13/2017 1:42 PM
34	Prescribed narcotic I was offered antidepressants on 8 separate occassions before I was diagnosed.	7/13/2017 6:13 AM
35	Psychological Yes, but interestingly only AFTER getting a POTS diagnosis. A few times I was essentially told that it wasn't a real disease and that I should try antidepressants.	7/12/2017 10:36 PM
36	Prescribed narcotic Psychological The first Dr. intimated as much - did a head CT (headaches he could understand)....sent me to other specialists most less helpful. One trip to the ER where ativan seemed to help (I was already telling folks it seemed blood pressure related since I felt better with my head down) - mine is a little adrenal sensitive. I eventually went to a psychologist and asked if I need her or an M. D. - she said M.D. and suggested a woman who wouldn't say it was in my head. various DR.s had suggested panic. I and my husband said no its not repeatedly.	7/12/2017 3:53 PM
37	Psychological My mom was told it was anxiety and to push me through it. Thankfully I have an amazing mom who believed me and kept fighting to find out what was really wrong.	7/12/2017 3:14 PM
38	Other Health Condition I was told I was dehydrated	7/11/2017 2:11 PM
39	Other Health Condition Psychological When my symptoms became very acute when I was 50 I was sent for psychiatric care. Not until I passed out driving and crashed my car did someone take me seriously and did a tilt table test. I've been very ill off and on since the age of 16 after a severe case of MONO. I was hospitalized for a month and on a Cardioligist service so evidently they saw cardiac issues way back in 1971. I also have auto-immune disease that was diagnosed at age 21. It has been a battle and now my entire autonomic system has symptoms. I'm scheduled at Vanderbilt this August. My Cardioligist insisted after the Neuroligy symptoms began last February.	7/11/2017 12:25 PM
40	Other Health Condition Psychological The first time by a neurologist, yes, because he couldn't find anything wrong with me after a virus, which misaligned my eye and caused blurred vision, he suggested his neuro-psychiatrist, and I walked out with a consult and never looked back. The neurologist sent me to a rheumatologist, who thought I could have Scleroderma, but didn't, and then I decided to see a cardiologist, because of irregular heart beats, where I was diagnosed with hypertension and hyperlipidemia, and I decided to go to an opthamologist, because of my blurred vision, and an ENT for dizziness and vertigo. I was diagnosed with a Binocular Defect, and Vestibular Neuritis. All of these findings happened over a period of about 5 years. I had a another virus which caused my eustachian tube to close and had to have a myringotomy to equalize the pressure in 2003. Then I coughed up frank blood from my right lung in 2004, without any good reason. But years later, after being very ill for about 4-5 years with insomnia, dizziness/vertigo, irregular heart rate, and flushing, and temperature issues, I prayed, and God found an ENT in Birmingham on the internet for me to see, who without my knowledge was familiar with autonomic vertigo, and then in 2011, I was sent to now the clinic that has been renamed and relocated called the Dysautonomia-MVP Center in Birmingham, AL, and after an EKG, Stress Test, Echocardiogram and Tilt Table, I was diagnosed with a Mitral Valve Prolapse, and Pure Autonomic Failure/POTS. A month later was diagnosed with Sleep Apnea, and a year later, I was diagnosed with Fibromyalgia, and Osteopenia in 2012.	7/11/2017 10:46 AM

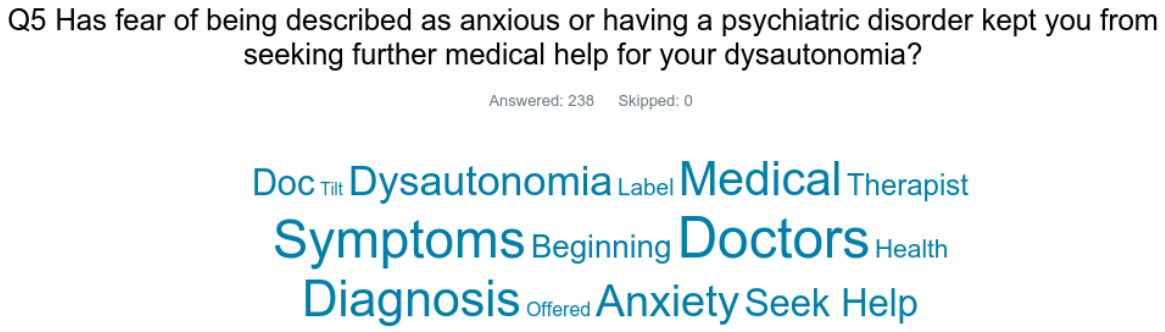
41	Prescribed narcotic Psychological Initially told it was probably anxiety but gradually got worse. Was prescribed Amitryptilline 10mgs but we thought this may help particularly with the sleep problems. Never told to seek psychiatric help but once referred to consultant for diagnosis, had to complete psychiatric questionnaire.	7/11/2017 10:39 AM
42	Other Health Condition Prescribed Non Narcotic My parents were told I likely had a brain tumor that science couldn't find. My actions and reactions were what they used. However I was sent home, then back to college. Years later, with a set of twins, a toddler, and infant. I was found passed out in a public restroom. My (now ex) husband thought I was drunk, yet I hadn't had anything other than water. I was 36. I found a cardiologist who recommended a tilt table test. I told him I was just hypoglycemic. The tile table demonstrated POTS, in short order I was put on corgard, etc. I was constantly dizzy and travelling for business. When that further impacted my children I changed jobs. Did not hear the name dysautonomia until 2006.	7/11/2017 9:52 AM
43	Other Health Condition My pcp didn't know what to think. He did a poor man's tilt in the office and said I was normal. Based on that he just kept sending me to gastro because of the constant nausea. Wasted three valuable years.	7/11/2017 9:33 AM
44	Psychological No, but I got the feeling that some people in the health care field thought I was overly emotional when i described my symptoms and couldn't get a definative diagnosis.	7/11/2017 8:34 AM
45	Cannot Categorize Yes, by ER doctors and PCP. Diagnosed within a few months by a cardiologist.	7/11/2017 8:30 AM
46	Psychological I was told my problems were anxiety. Actually I do have adregenetic POTS and in retrospect my anxiety disorder needed to be treated to help my POTS. However the POTS is also a separate disorder.	7/11/2017 8:02 AM
47	Psychological Yes - had symptoms for many years and saw several doctors. Some called it depression, But then later was became more pronounced, was taken more seriously,	7/11/2017 7:26 AM
48	Other Health Condition Prescribed narcotic I was diagnosed with vertigo and take 2mg valium as needed. I have completed Vestibular PT which did improve my balance, muscle strength and overall endurance.	7/10/2017 11:12 PM
49	Other Health Condition Prescribed narcotic both and my memory is terrible. eventually I was told I had CFS in late 1980s chronic fatigue syndrome.	7/10/2017 10:57 PM
50	Other Health Condition Prescribed narcotic Psychological Yes, and then some. Diagnosed with severe vertigo, anxiety/depression, and hyperventilation syndrome among many things.	7/10/2017 9:33 PM
51	Other Health Condition Prescribed narcotic Psychological Got wrong DX of early Parkinson, told I had anxiety or some other disorder. Tried on SSRI and SNRI that made everything worse. Long story. Probably have had POTS most of my life. And late in life got a DX.	7/10/2017 9:14 PM

Question 5: Has fear of being of being described as anxious or having a psychiatric disorder kept you from seeking further medical help for your dysautonomia?



A little over half of the survey responders stated being described as anxious or having a psychiatric disorder has not kept them from seeking further medical help. Unfortunately, 47.48 % still have strong concerns and because of it sometimes avoid treatment.

Answer Choice	Response %	Number
Yes.	27.73	66
No.	51.68	123
I don't know.	.84	2
Other (please specify)	19.75	47
Total		238



The replies demonstrate many of the concerns over being falsely identified as having mental health issues; it has kept some from seeking care for their symptoms. The words Doctors, Symptoms, Diagnosis,

Medical and Anxiety were used for samples for this analysis. 'Doctor' was further sorted into Negative and Encouraging or Good Advice. 'Medical' was sorted into Negative and More Positive.

Doctors: Negative

I had a positive diagnosis by the autonomic neurologist's at the Rochester Mayo Clinic in 2001. This helped me, but I still run in to doctors that know nothing about POT and after spending all my energy explaining it and telling them about my diagnosis ask me if I am anxious. So every new doctor I get, this scares me. 7/15/2017 4:27 PM

Yes. Even after having a POTS diagnosis, I've had doctors who weren't familiar with my history suggest that my problems were all in my head. One told me that only medical quacks diagnosed POTS, one (a resident right out of med school) told me he'd learned that there was controversy over whether POTS was real, and twice I was offered anti-depressants because my "physical symptoms were a manifestation of depression". Again this all happened AFTER getting a diagnosis. 7/12/2017 11:36 PM

Doctors: Encouraging or Good Advice

It did for a while, but I was lucky to have the support of my family to keep looking to find a doctor who believed in my and believed that my symptoms were real. 8/1/2017 6:52 AM

It did cause me significant stress and delays in finding treatment between doctor rejections, but my symptoms and a supportive husband helped me to persist. 8/9/2017 3:38 PM

Symptoms:

It has stopped me from going to the ER for symptoms . 7/13/2017 11:15 AM

I suppose because I no longer knew to continue searching for another diagnosis. I was convinced for a long time it was all symptoms due from anxiety. 7/29/2017 4:26 PM

Diagnosis:

With past HX of psychiatric diagnosis and all the treatment and labelling that came with it, was gun-shy of receiving another diagnosis that remains in a nebulous status re definitive tests, tx recommendations, outcomes, acceptance in medical community. 7/11/2017 10:01 AM

It hasn't stopped me from seeking care but it certainly has led to unnecessary stress. The people who are supposed to help me are instead mislabeling me which keeps me from finding my real diagnosis and successful treatment. 8/31/2017 11:38 AM

Medical: Negative

I sought other medical help anyway but about half of the medical professionals did not know about dysautonomia and thought it was a form of depression or "hysteria". 7/10/2017 10:09 PM

I kept having to go to the ER for many different medical events. I was told I should stop coming to the ER for attention...that I needed concealing. 8/12/2017 12:19 AM

Medical: More Positive

It has not stopped me from seeking medical help, but I've been quick to discontinue treatment from people who suggested anxiety. 9/2/2017 11:35 AM

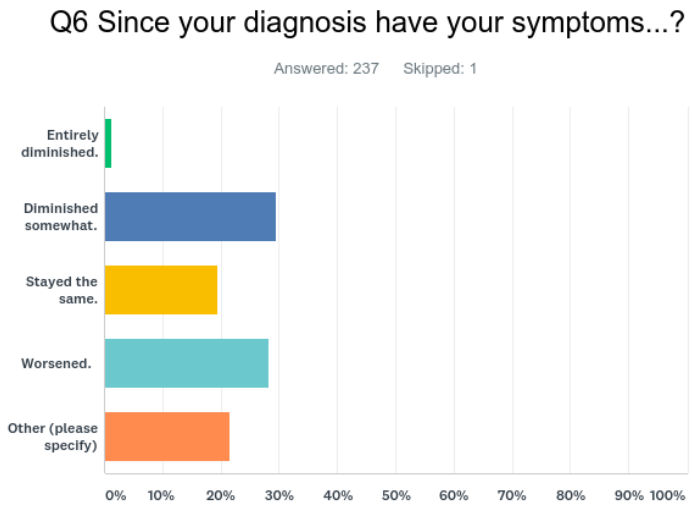
Anxiety:

I've never sought help for depression and anxiety lest that impacts my dysautonomia care 8/31/2017 11:04 PM

Dysautonomia:

I think a long-term, mismanaged RX to and withdrawal from benzodiazepines initiated my dysautonomia that later became dramatically worse after an accident and surgery. 7/10/2017 11:45 PM

Question 6: Since your diagnosis have your symptoms…?



Question 6 had 237 responses with one skipped.

The numbers speak for themselves. The vast majority have not improved.

Questions	Response %	Number
Entirely diminished.	1.27	3
Diminished somewhat.	29.54	70
Stayed the same.	19.41	46
Worsened.	28.27	67
Other (please specify)	21.52	51
Total		237

While less than 2% of the respondents reported their symptoms entirely diminished, many of them expressed that over time, through medication, therapies and learning to better manage their symptoms, they have improved. Some remain the same, and some their symptoms are fluctuating or have worsened. The words Symptoms, Worse, Worsened, Diminished, Fatigue and Diagnosed were used for

samples for this analysis. 'Symptoms' has been further sorted into Fluctuating and Controlled with Management.

Symptoms: Fluctuating

Some have diminished, others have worsened. The definite consistent pattern is that you be grown more adept at managing my symptoms and pacing myself and my expectations for myself accordingly. 7/11/2017 7:48 AM

I experienced a time after my diagnosis and beginning of treatment that I would consider almost a remission, I was relatively healthy, albeit not as strong or energetic as a normal 27/8 YO. After about 18 months my symptoms started coming back until I am quite ill again, probably not as unwell as I was initially, but definitely significantly worse than I was and consistently deteriorating. 8/1/2017 6:52 AM

Symptoms: Controlled with Management

I've had symptoms since my teens and no one could figure it out. I was diagnosed accidentally because of passing out while driving. Now that I'm aware of all of the symptoms , the puzzle is fitting together. 7/11/2017 1:25 PM

My symptoms are managed with medication, lifestyle changes, and diet. Otherwise they would flare up like they were when I was diagnosed. 7/23/2017 11:39 PM

Worse:

The pendulum is swinging further apart. The bad days are getting worse and the good days are getting better. The pressure waves and no-pain-migraine light shows are getting worse and my higher-energy days seem to give me a few more hours off my bed. 7/11/2017 12:12 AM

More a stepwise progression over the years. Gets worse , stabalizes for a while, gets worse again, then stabalizes etc 8/31/2017 6:51 PM

Worsened:

Worsened in some ways and gotten better in others. Finding right combo of med makes a difference. 7/10/2017 10:14 PM

Rapidly worsened especially gastric issue. 8/29/2017 8:30 AM

Diminished:

Diminished but only by I take Bysoprolol, Clonodine, Mestinon and Cymbalta. 7/11/2017 2:00 PM

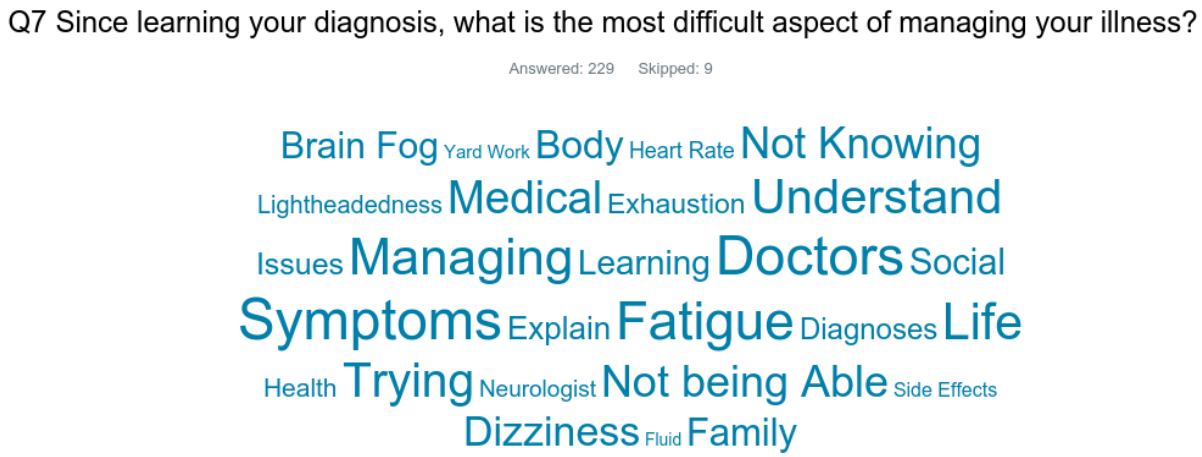
They have diminished a little with the help of right medication. 7/14/2017 9:37 AM

Fatigue:

Tachycardia is under control. Still have overwhelming fatigue . 7/28/2017 4:05 PM

I have lowered my heart rate through oral hydration and increased salt intake but I still have chronic fatigue , headaches, brain fog, GI issues and muscle weakness. 8/31/2017 11:38 AM

Question 7: Since learning your diagnosis, what is the most difficult aspect of managing your illness?



Most of the respondents reflected concerns over daily management of multiple symptoms , their frustrations of having to explain symptoms and management to disbelieving family, friends and medical personnel--new to them or not. They shared their difficulty with putting together a team of adequately educated and trained doctors, and their continuing struggles with the complexity of keeping track of many appointments and medicines. Words used for this analysis are Symptoms, Doctors, Fatigue, Managing, Life, and Understand.

'Symptoms' were divided into Difficult to Control and Multiple.
Responses for 'Doctor' split to either Undereducated or Dismissive.
'Fatigue' split into Quality of Life and Health.
The word 'Managing' provided search results for manage and management and has been broken down into Time, Others and Medical.
'Life' divided into Limitations, Employment Problems, and Struggling to Cope with Symptoms.
'Understand' split into Varying Symptoms and Frustration.

Symptoms: Difficult to Control

Getting the med dosage just right and also finding my limits and not hitting them. I tend to just push through the symptoms . 7/11/2017 5:40 AM

Controlling the stress and hormonal fluctuations and influence the severity of my symptoms , as well as explaining an "invisible" disability to people. 7/12/2017 4:12 PM

Symptoms : Multiple Symptoms

People, even doctors, don't understand the illness or just how much little things can so severely wipe me out. They don't understand the vast multitude of symptoms , not just heart rate or how intensity of symptoms varies day to day, even minute to minute 8/31/2017 1:39 PM

Realizing what all can be affected by NCS. For years I just thought it was the head rush. Had no idea the itchy legs when standing, finding cooking nauseating (standing + heat = ewww), vestibular dizziness, bowel symptoms , temp intolerance, etc., etc., could all be a part of NCS. I went through a full stress test & 24-hour holder monitor for chest pain only to find out online chest pain isn't uncommon with NCS (but the PCP is clueless, and I'm not sure I'd want chest pain easily written off as NCS either). Eventually I'm hoping they'll link up the Raynaud's and other quirky things my body does...but I'm not holding my breath (just my phone, while lying in bed, and my hands are all numb & tingly due to lack of blood flow). 7/26/2017 2:40 AM

Doctors: Undereducated

I was going to a electrical cardiologist who didn't know much about it. I recently found I am going to the wrong specialist and none of my doctors knew. I am now going to a disautonomic neurologist. Lack of info for doctors and myself. 7/30/2017 10:32 PM

Trying to know what this days dysfunction will be, and what pain and diminished function comes with it. will it be my sympathetic, parasympathetic or my enteric autonomic system that will stop my day. Then managing medical professionals who have no idea about Dysautonomia, and how to deal with a patient with a rare, progressive and incurable disease that no one has even heard about. ...like my cardiologist said I will always know more than my doctors about this disease. Before I accepted it I would say the depression was hard. 8/12/2017 12:19 AM

Doctors: Dismissive

Friends, family, work, etc not understanding what my limitations are and thinking that I am lazy or need to work out more or am just too sensitive. It's also hard to deal with doctors who only want to treat the symptoms and just throw pills at me instead of actually trying to figure out an underlying cause or who get frustrated when those pills aren't working and seem to give up on treatment. 8/9/2017 5:29 PM

The stress of needing treatments that are available (not to mention what isn't available) and having medical gatekeepers (doctors , specialists, admin assistants, etc.) not help, but instead dismiss, condescend, and generally make it more difficult to access necessary help. 9/1/2017 11:45 PM

Fatigue: Quality of Life

Can't narrow down to just 1. It's a lifestyle. I would say that the most troubling are the presyncope, tachycardia, shortness of breath, and fatigue (NOT in any particular order). 7/10/2017 10:30 PM

Trying to keep up with normal, basic activity (showering, housecleaning, errands, etc.) Pain, fatigue , anxiety has left me with a poor quality of life. But, the worst part is, I feel awful all the time, and nobody believes me. They think I am being lazy or making it up. 7/27/2017 3:31 PM

Fatigue: Health

Managing the fatigue and dealing with the after effects of deconditioning such as degeneration of the lumbar spine. 7/10/2017 10:09 PM

The fainting spells and extreme fatigue . 7/11/2017 8:42 AM

Managing: Time

The fact that it takes so much time to finally be managed. I still struggle with fatigue and brain fog and not sure how to get rid of it or have it better managed. It's also difficult for me to know when I have to take it easy when working out because I was a collegiate athlete and I'm not used to this. However, if I don't take it easier I feel the effects for hours to days afterward. 7/28/2017 4:39 PM

Also managing my kids and my business. Having to RE-arrange my life or entire days or weeks to my illness. The unpredictability of being able to plan ahead because I don't know if it will be a decent day or a bad day. 8/15/2017 8:54 PM

Managing: Others

managing the dizzy spells and visual disturbances at same time... most people have no idea what you are talking about so they think this is a made up condition 7/17/2017 9:07 PM

Living alone while struggling to manage symptoms and fearing I may become permanently disabled without a safety net. 8/7/2017 8:18 AM

Managing: Medical

My ANS has attacked my heart and lungs, making management very difficult. Also looking into MCAS and hEDS. 7/13/2017 12:14 PM

Loss of quality of life and managing the new normals that change as my body changes 8/31/2017 9:27 PM

Life: Limitations

Adjusting my life to the fact that I have to consider my health in almost everything I do and every decision I make. It just totally reframed how I look at my life . Even during periods when I'm more stable, I have to be aware of how easily I can throw myself into a flare - it's affected everything from major decisions about work, grad school, and relationships, to minor things like whether I can go outside on a summer day, or eat a particular meal, or stand in a long line at the store. I've definitely adjusted to this, but when I think about having to do it for the rest of my life , it's a bit overwhelming. 7/12/2017 11:36 PM

Changing my entire way of life , and using a wheel chair. 9/2/2017 8:21 PM

Life: Employment Problems

I was laid off at work, and not touchable for life insurance. 7/11/2017 10:52 AM

Total loss of employment, and social / physical activity. I can no longer hike or work out. Quality of life ruined. 9/2/2017 11:35 AM

Life: Struggling to Cope with Symptoms

Managing life with a chronic illness is a constant struggle and has always been difficult before and after correct diagnosis. 7/22/2017 3:18 PM

Trying to keep up with normal, basic activity (showering, housecleaning, errands, etc.) Pain, fatigue, anxiety has left me with a poor quality of life . But, the worst part is, I feel awful all the time, and nobody believes me. They think I am being lazy or making it up. 7/27/2017 3:31 PM

Understand: Varying Symptoms

The waxes and wanes. Others understanding I have a chronic condition with flare ups 7/11/2017 4:49

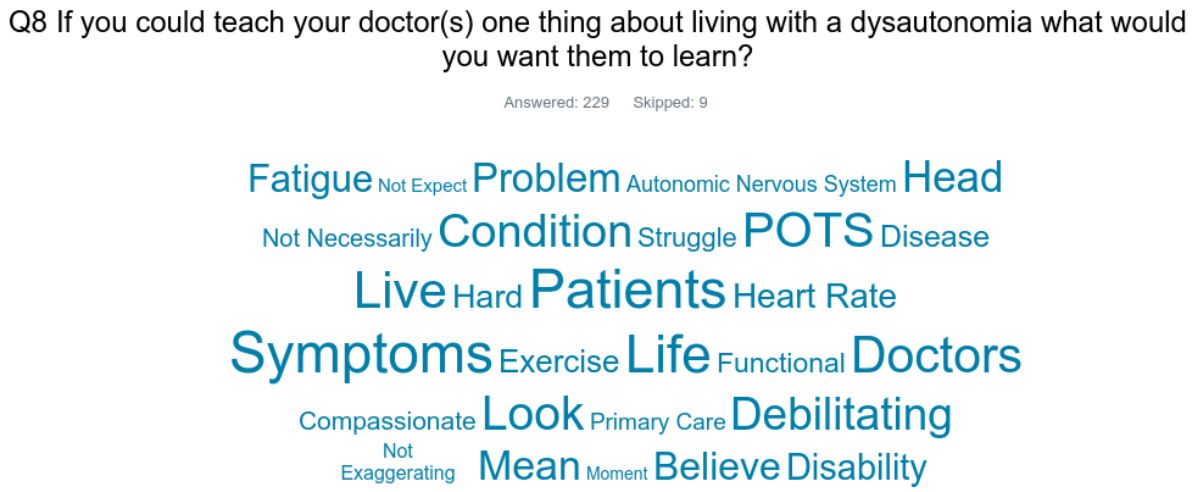
the constant unmitigated uncertainty, and also feeling like I'm letting down my family down all the time when I can't do things. Feeling like no one really understands . 8/1/2017 6:52 AM

Understand: Frustration

The illness is invisible and not obvious to those who do not know. This makes it hard for some to understand . 7/10/2017 10:14 PM

The lack of knowledge on the part of physicians. The inability of even the best of friends understanding that I just can't do "all that" and still be well enough to work part-time or cook dinner. 7/12/2017 4:53 PM

Question 8: If you could teach your doctors one thing about living with a dysautonomia, what would you want them to learn?



Respondents strongly expressed discontent over their doctors not knowing the names or basic symptoms of dysautonomias and their inability to conceive that such varied symptoms could exist together, leading to disbelief of the patient and oftentimes ending with a prescription for a mood enhancing drug instead of forwarding the patient to another specialist for diagnosis. Many replies showed concerns that doctors should be more aware of how dysautonomias are negatively life-changing. Some respondents were also unhappy that 'looking well' at a doctor visit worked against them. The words Symptoms, Patients, Life, Lives and Doctors were used for samples for this analysis. The word 'Lives' also provided search results for lived and living.

'Symptoms', of Question 8, is the highest response word in the entire survey. It has been sorted into five groups: Multiple Symptoms, Hysteria, Educational, Quick Onset, Challenges, and Positive.

Symptoms: Multiple Symptoms

Zebras do exist. When your patient keeps presenting you with symptoms that don't seem to make sense, look beyond. Look beyond labeling them with anxiety and passing out pills. Look beyond our youth, if an older patient described the same symptoms what would you think to test for? Look beyond basic labs and scans, if they read normal and your patient is still complaining of symptoms it's not all in their heads, there's something else going on that you just haven't found yet, where would you look now? Look beyond the usual and the obvious to see and acknowledge the rare and 9/1/2017 9:25 AM

We are ALL different, not just in diagnosis, but every day! Our symptoms may or may not mirror your last patient, just as those things that help us are different. 7/11/2017 10:52 AM

Symptoms: Hysteria

It's not mentally derived. These physical symptoms aren't just manifestations of me being unmarried and no children in my thirties, or Anxiety, or "mood disorder" or "conversion syndrome". I'm not an "anxious patient" I'm someone fighting to save their life and not end up in nursing home for the next 60 or so years or worse... I have thyroid issues confirmed and potentially something else easily manageable/treatable that could make my Dysautonomia symptoms subside, but you've all been too busy telling playing Psychiatrists, to actually study what this could be and order the tests... meanwhile I've lost years of my life, quality of life, relationships, friends, finanacial stability and dignity waiting for you to "Do no harm" and help me... (sorry that's my pent up frustrations surfacing too, but it's sincerely how I've been made to feel and derived from actual things doctors have said to me) 8/31/2017 10:16 AM

I'd like to point out how strong we are despite living with a chronic illness that is perceived by the majority of the medical community as a self induced mental health condition. Not to mention the toll it takes on one being treated for something that isn't the problem, and dealing with the possible new symptoms that arise and potentially make POTS worse. The Hippocratic oath that doctors pledge to is suppose to serve as a contact for doctors to work towards the benefit and health of the public. Refusing to acknowledge or become familiar with the unknown is, in my opinion, an ethical violation of the Oath and a major disservice to all those suffering from POTS as well as future generations to come. 7/12/2017 12:09 PM

Symptoms: Educational

NCS is chronic. Too often I see it described as "episodic, patients feel well between episodes." Sure, I feel well between episodes...until it's evening and I'm flipping exhausted because it's my 30th episode that day. Dr. *NameDeleted* says that 95% of those who have chronic OI have POTS. So what are those of us who have chronic, daily symptoms of OI that have a bp drop upon standing followed by a vasovagal response rather than a sustained hr increase? Chopped liver? Why are patients who have daily dysautonomia symptoms given the same label as those who only faint at the sight of blood? And *ExpletiveDeleted*, can we please get the various forms of dysautonomia standardized, diagnostically, with one label per diagnosis? NCS, NMH, VVS, NMS, POBS,...I'm sorry, you have what? Depends on which doctor you talk to? How can we ever hope to make gains in research if we haven't even organized the basics? 7/26/2017 2:40 AM

BPs & pulse are usually only taken while seated. The major symptoms don't show up until someone is standing and staying still for a period at least 3 minutes. Please take the time. It can be illuminating. 8/9/2017 12:24 AM

Symptoms: Quick Onset

It is very unpredictable - you can feel perfectively fine one second and feel very ill the next second. Also, not always knowing what triggers symptoms ; it can be a change in temperature (eating/drinking cold foods can be a trigger) , hypersensitivity to odors, sounds and different types of lighting, but not knowing when or why they trigger symptoms and other times not. It sucks! 7/10/2017 10:44 PM

Symptoms change in an instant. Even though the vitals read one thing in the office, they may be completely different shortly thereafter. Listen to your patient and do monitors (heart and BP) that measure for 24-48 hour periods. 7/12/2017 8:25 AM

Symptoms: Challenges

Quality of life matters in health care. I may not be dying but symptoms make living a real challenge for some with dysautonomia 7/11/2017 4:49 AM

That I don't have all the time in the world to start feeling better. These symptoms are debilitating to some degree, and make it so difficult to live a normal life and be able to work. 7/28/2017 4:39 PM

Symptoms: Positive

My GP was quickly responsive and identified based on my symptoms . Within fifteen minutes she'd pared down my symptoms and referred me to a cardiologist who specializes. 9/2/2017 5:57 PM

That we are all different and that they need to learn we are all affected differently but more importantly to understand the condition exists and when patients present with a set of symptoms which point towards the diagnosis then get down and get the patient diagnosed. Then, write a kind of personal health passport for each individual so if that person has to be taken to emergency care or admitted to hospital...all staff can see the issues and will know how to empathise and accommodate the individual instead of that individual having to try to explain it when they are too ill or too weak to do so. 8/29/2017 8:30 AM

'Patients', of Question 8, is the next highest response word in the entire survey. It has been sorted into four groups: Educational, Invisible Illness, Balancing Life, and Hysteria.

Patients: Educational

Make the patient an active partner in their treatment plan. Explain why certain treatments are being ordered, and the pros and cons of compliance/noncompliance. You may only see the patient every 4-6 months, but they live with this every day. 8/10/2017 5:35 PM

A multidisciplinary team is so very important. It's their responsibilty to communicate with other specialists to get the best rounded care for the patients , as many different body systems are involved. You may not be able to cure us but you can help our quality of life by checking your ego or frustration at the door and working with others as a team which includes the patient as part of that team. Do not forget we come to them because we can't do this on our own. We understand frustration, annoyance, confusion, defeatism, we live it everyday, we need you to believe us, listen to us, do not dismiss us because we are complex, stand by us to help us feel we can do this one day at a time. 8/31/2017 9:27 PM

Patients: Invisible Illness

It is very isolating if you are bedridden, but for all POTS patients , please do not judge a book by it's cover. Listen to what the patient tells you instead and investigate it. Please do not judge how ill we are by how we look or by the notes we have with us or take during the appointment. How we look - When a person is sick, we have the same standards of how we want to look while we are sick that we had when we were well. Nobody wants to look sick. So if we look good, it doesn't mean we are well. It takes us a huge amount of effort to try and look our best once we are ill. Everyone, healthy or sick wants to look as good as we can. For POTS patients , it takes days to prepare for an office visit. Deciding what clothes, jewellery and makeup to wear will not happen when we are having a high brain fog day. I won't even remember what I own on a high brain fog day. So, if we get to an appointment looking awful, we did our best. On the other hand, if we had lots of notice for our appointment or had someone who could help pick out everything for us, we could look very well put together. It takes us longer to do everything, even simple things, compared to when we were healthy. This includes things like getting dressed. Also, it might have taken us 4 hours to put our makeup on, as exertional fatigue limits how fast we can do everyday things. If we are having excessive sweating, we might have to remove the part of the makeup we have on and start again 4 times before we get it on. We know we are sick and we don't want to look like we are. There are some POTS patients that do not look sick, no matter what they wear and with no makeup on, but they are extremely sick. POTS Patients Notes - There are POTS patients like myself, that have been collecting notes for +15 years and had some help from others to type it. So, if a patient shows up with a lot of notes, they didn't just whip them up in a month, week or day. If they wrote the notes themselves, they had to proofread 10 times or more and found mistakes in spelling and grammar each time. Our brain fog makes it extremely difficult. The reason it is so important for us to have notes to give at our appointments and to take notes while we are there, is that we don't know how clear our mind is going to be at that appointment and know we will forget to tell the doctor important things, we will forget the questions we wanted to ask and we will not remember what the doctor told us when we leave the appointment. If someone hands you a lot of notes, it's because they are desperately trying to get better. If they weren't very sick or didn't care, there wouldn't be any notes. BUT, there are probably POTS patients who might not have a high enough IQ that just can't do it (even when they were well) or their iIQ is normal but they have no days when their brain fog is well enough for them to do it between when the appointment was made and the appointment day. 7/15/2017 4:27 PM

Please trust your patients ' knowledge and intuition about their own bodies and conditions, and know that they may be incredibly sick, suffering, and disabled throughout their daily lives, even though they appear fine. 9/1/2017 11:45 PM

Patients: Balancing Life

The overall limitations of putting effort into one aspect of your life/health, lessons the amount of effort you can put into other aspects of your life greatly. Balanced life for dysautonomia patients is nothing like blanced life for a non-dysautonomia patient . 7/10/2017 10:33 PM

Invest in your patients - we are wonderful people who want to contribute to our communities and impact the lives of our families and loved ones. Please help us, our visits may take a little longer than the average patient but you are literally saving our lives. 7/14/2017 10:04 PM

Patients: Hysteria

It's not in your patient 's head-listen to your patients and don't make your patients self diagnose like I had to!! 7/14/2017 9:25 PM

Be OPEN MINDED that your patient might ACTUSLLY BE SICK and not just stressed, nuts, or hypochondriac.. 8/31/2017 1:39 PM

'Life', of Question 8, has been sorted into three groups: Life Altering, Daily Struggle, and Educational.

Life: Life Altering

I DON'T HAVE ANXIETY OR MENTAL ILLNESS, EDUCATE YOIURSELVES BEFORE MAKING ASSUMPTIONS!! DO DRS REALLY THINK IT'S ENJOYABLE TO BE STUCK AT HOME, ILL ALL THE TIME? QUALITY OF LIFE DWINDLES & EVERY ASPECT OF MY LIFE BEGAN A DOWNWARD SPIRAL. I YEARN FOR MY OLD LIFE & MY BODY TO COOPERATE!! AND 'NO' I CAN'T WILL IT, OR PRAY IT, AWAY. FED UP HEARING THAT STATEMENT TOO! 7/11/2017 10:16 AM

That it is incredibly debilitating, and we are doing our best to keep persevering in spite of our disability. It may not be a life -threatening diagnosis, but it is life -altering in the most fundamental ways. 7/16/2017 7:43 PM

Patients: Daily Struggle

That I live with the fear that fainting will result in serious injury or death every day of my life . 7/29/2017 12:38 AM

We are hard workers. We are motivated to work hard and get better. We aren't sick because we are lazy. We are sick because we are sick! Lying in bed for most of the day is not pleasant or fun. TV gets very boring. We want to live an active life . We just can't. 8/31/2017 3:45 PM

Patients: Educational

I would like the health community as a whole to learn that menstruation has a huge impact on a woman with dysautonomia's ability to live a regular life . I would like for health care providers to respect a woman's choice when it comes to their own reproductive organs especially when they are causing such

That it's HARD. Every single day is a struggle, and this is something that affects my entire life . And for doctors to not just go on statistics. I don't care if I'm "young and generally healthy"...medical conditions don't discriminate. So maybe instead of saying I "don't fit the statistic", write a new book. In every statistic, there is an outlier. 8/31/2017 10:56 AM

'Live', of Question 8, has been divided into two groups: Symptoms and Impact

Live: Symptoms

The fatigue associated with it...and that Sinus Tachycardia and chest pains can be difficult to live with. 8/7/2017 8:26 AM

That when we're in pain we're not really living , just surviving. I had a doctor tell me when he couldn't figure out what was wrong that since I had already survived 20 years and so clearly I was going to fine without a diagnosis and that wasn't okay. 8/10/2017 9:17 PM

Live: Impact

We have families, friends, jobs and we are here on this planet for a reason. This illness is affecting our lives . If you really want to try make a difference and change many lives , this is one way. We can't do it without you. 8/26/2017 7:19 PM

there is no way in hell anyone would ever choose to live like this. 8/31/2017 10:44 AM

'Doctors', of Question 8, has been sorted into two groups: Educational and Real

Doctors: Educational

That there ARE medical professionals out there (like my neurologist, who diagnosed me) who can help them learn more. I would love to see just one person saved from the hell I had to endure. If I hadn't fought for myself, my original doctors would have given up. 7/12/2017 4:12 PM

I would like my doctors to educate themselves about dysautonmia instead of me always bringing things to their attention. 7/21/2017 10:09 AM

Doctors: Real

That it's real. That they do not need to make me undergo all the diagnostic tests again just because I am new to their practice. I bring my sheaf of papers from the Mayo Clinic where I was finally diagnosed when I get new doctors or specialists and yet they want to redo the painful and exhausting tests just to "see for themselves." I can't help but think this is done because they find it too difficult to believe dysautonomia happens without prior Parkinson's or cancer. I'm a rare case, I know. But I'm still a valid case. 7/11/2017 7:48 AM

That we often don't say how we're really feeling at a particular time. That we sometimes feel very defeated by our own bodies. That we sometimes wonder if our heart will just stop one day. That we feel quite normal when (in my case) sitting and long for the day when we can feel that way upright or doing activities. We wonder how it can be such a different world from one minute to the next. We wonder what each and every new nurse and doctor we see is thinking when we're in with them. do they believe us? 7/29/2017 1:06 AM